



**Annual National Early Hearing Detection and Intervention Meeting**  
**Atlanta, Georgia**  
**Renaissance Atlanta Hotel Downtown**  
**February 23-26, 2003**

**Session Descriptions**

<b>Sunday, February 23<sup>rd</sup></b>	
Session Code	V1
Session Title	<b>“Sound or Silence” Documentary and Discussion</b>
Session Description	This documentary focuses on the decision-making process of adults considering cochlear implants and of parents determining the communication mode that is most suitable for their child(ren). <b>The issues and emotions (fear, isolation, awareness of deaf culture)</b> involved in assessing the options available and the consequences of the choices made will be discussed by families who have been faced with this difficult process. One woman’s life is followed as she gathers information about cochlear implants, <b>faces the fear of surgery involving the brain, along with the hope of being able to hear once again.</b> Ultimately she has the surgery, then realizes she will need to re-learn how to hear as well as speak. <b>Fear, anger, frustration, hope, and joy are all real emotions faced by families when making choices about lifetime communication commitments.</b>
Moderator	Judith Gravel
Session Code	M2
Session Title	<b>“Sound and Fury” Documentary and Discussion</b>
Session Description	This documentary and discussion focuses on two brothers, one deaf and one hearing, who grapple with a decision concerning their deaf children. The debate that rages through the extended family turns less <b>on technology and medical concerns than social politics and culture.</b> The deaf parents of a school-age girl fear what the implant would do to her <b>unique identity</b> , while the hearing parents of a toddler see no question at all when it comes to making a lifetime commitment to a communication mode. <b>All sides have their say, but ultimately the increasingly angry arguments reveal prejudices and fears</b> from both sides and split the once-harmonious family, much like they have split hearing and deaf communities across the country.
Moderator	Sharon McNeal

Monday, February 24 <sup>th</sup>	
Session Code	PL1
Session Title	<b>Opening Session—General Welcome and Introductions</b>
Session Description	As newborn hearing screening becomes a standard of care, it is important for states, professionals and others involved in setting up EHDI programs to be aware of the resources available, and current activities happening, at the national level. In the opening session, the directors of five agencies involved in EHDI will provide information about their services. Dr. Cordero will explain <b>CDC’s role in developing systems for tracking and follow-up</b> after the initial hearing screening. The availability of <b>HRSA funding to promote newborn hearing screening and develop statewide EHDI programs</b> will be discussed by Dr. McPherson. Dr. Mele-McCarthy will explain the <b>Dept. of Education’s role to provide special education services for children identified with hearing loss</b> . <b>NIH’s role in EHDI is to conduct research related to deafness and other communication disorders</b> and will be addressed by Dr. Allen. The role of <b>Family Voices is to advocate for the inclusion of a set of basic principles in every health care reform proposal</b> and will be presented by Ms. Cernoch of Family Voices. Each of these speakers will provide contact information for their agencies
Speakers	José F. Cordero, Merle McPherson, Joan Mele-McCarthy, Marin P. Allen, Jennifer Cernoch
Session Code	PL2
Session Title	<b>“Screening and Assessment: Emerging Technologies &amp; Protocols”</b>
Session Description	This plenary session will provide an overview of what factors are involved in setting up a comprehensive EHDI program. The advantages of using the <b>minimum OAE device</b> , primarily cost and simplicity, will be compared to the advantage of the accuracy of AABR equipment, and the time effectiveness and low refer rate of a two-stage system utilizing both kinds of technology. <b>A protocol using tone burst ABR, bone conduction ABR and ASSR to provide a complete pediatric diagnostic evaluation</b> will be presented. <b>Difficulty in getting parents to return to have their child re-screened or diagnosed will be discussed, communication break down between providers, and other unique situations are common barriers to conducting timely audiological diagnosis</b> . However, the importance of early diagnosis so that intervention can begin as soon as possible will be stressed.
Speaker	James W. Hall
Session Code	PL3
Session Title	<b>“Transitions: Screening to Diagnostics to Early Intervention to School”</b>
Session Description	This panel features a parent of a child with hearing loss, a representative from Part C, and a state EHDI coordinator discuss how to best meet the needs of families through the EHDI process of screening, diagnosis, early intervention and school for children with hearing loss. One <b>difficulty of completing the screening process is returning to the hospital for a re-screen if it involves an additional hospital charge, transportation problems or scheduling problems</b> for new parents who may already feel overwhelmed. <b>The cost of the diagnostic procedures, which are not covered by all insurance companies</b> , and the <b>difficulties for people living in rural areas where services are limited</b> will be discussed. <b>Limited access to early intervention</b>

	<b>services</b> will also be addressed. The <b>need for professional training to specifically deal with infants with hearing loss</b> , the <b>role of a child's medical home in ensuring that diagnostics and enrollment in appropriate intervention services occur promptly will be emphasized as successful strategies for ensuring smooth transitions</b> . The problems encountered when children transition from early intervention into school systems will also be addressed.
Speakers	Kathy Thompson Whaley, Martha deHahn, Weilin Long
	<b>Workshop Breakout Sessions</b>
Session Code	A1
Session Title	<b>Bringing Families Together</b>
Session Description	<b>The state of Alabama uses the services of the Alabama Ear Institute to help families of newly diagnosed children with hearing loss connect with families who have been through the same experience</b> of learning that their child has a hearing loss. <b>Regional support groups</b> are available for parents as they face decisions that will affect every family member, not just the child with hearing loss. <b>A mentoring system</b> is set up, so that new parents have someone they can call to answer questions or share emotions about what they are experiencing. <b>The state of Michigan has funded a position for a parent consultant. Parents</b> whose child is diagnosed with a hearing loss receive a card inviting them to <b>call the parent consultant, who can answer questions and provide emotional support. The parent consultant serves as liaison between the EHDI program, parent groups and agencies serving children with hearing loss.</b> The parent consultant is the mother of a child who is hard of hearing.
Moderator	Karen Munoz
Speakers	Casey Arnold, Debra Bailey, Amy Lester
Session Code	A2
Session Title	<b>Developing and Providing Unbiased Information</b>
Session Description	This session will focus on how states can develop and provide unbiased information to parents regarding early hearing detection and intervention. <b>The role of the audiologist, physician, state, and early intervention programs is to seek input from a diverse group of professionals, families, persons with deafness when developing materials</b> to ensure that families are provided with an unbiased array of communication options. <b>Current biases include professional preferences for one communication mode over another (i.e., medical intervention versus using sign language). Factors to consider when developing materials include deaf culture, religious and cultural background, family needs, financial barriers.</b>
Moderator	Krista R. Biernath
Speaker	Rosalyn Proctor; Anne McNally
Session Code	A3
Session Title	<b>On-going Tracking for High Risk Conditions</b>
Session Description	Current efforts to track children at risk of developing late onset hearing loss will be provided. An overview of what risk factors should be included in EHDI tracking systems, methods for capturing the data, and challenges related to tracking children with risk factors. <b>Some risk factors to be discussed for inclusion in EHDI systems include family history of hearing loss, CMV, craniofacial anomalies, meningitis, medication, pulmonary hypertension, rubella, seizures, sepsis, and syphilis exposure. Methods for tracking risks can include paper-based letter writing efforts, reminder/recall</b>

	<b>systems, and tracking databases such as Access. Challenges include lack of developed surveillance and tracking systems, lack of communication between providers, lack of concern by families, general lack of information.</b>
Moderator	Pam Costa
Speakers	Betty Vohr, Leslie Beres-Sochka, Judith Gravel
Session Code	A4
Session Title	<b>Early Intervention</b>
Session Description	Three different models of state-based early intervention services will be presented in this session. <b>Wyoming utilizes an innovative approach providing feedback for parents by videotaping the parent's interactions with their child who has a hearing loss.</b> This allows the early intervention specialist <b>to provide support and suggestions without needing to be on-site</b> with the child and parents. <b>Colorado has developed a regional deaf role model program, which offers support and education to families on a regional basis.</b> They have also <b>trained professionals to work with infants who have hearing loss</b> , and are providing parent support to families who speak only Spanish. <b>An early intervention program for children with hearing loss is operated by the Idaho School for the Deaf and Blind.</b> There is an <b>outreach program</b> which serves families who have a child, birth to five years. The <b>philosophy of the program is that each family should have the opportunity to obtain comprehensive services regardless of the mode of communication they use.</b> The goal is for every family member to be able to communicate fully with the child who has a hearing loss.
Moderator	Karen Ditty
Speakers	Arlene Stredler Brown, Emma Lozada, Nancy R. Pajak
Session Code	A5
Session Title	<b>EHDI Check Up: Examining the Health of Your State Law (AAP)</b>
Session Description	Faculty from the American Academy of Pediatrics will engage participants in an interactive session to discuss strategies for developing new or <b>enhance existing legislation by drafting specific language or by opening existing laws for modification.</b> Representatives from <b>states with successful EHDI legislation will share their advocacy experiences.</b>
Speakers	James G. Pawelski, Judith C. Dolins, Dolores Orfanakis
Session Code	A6
Session Title	<b>Providing Effective Continuing Medical Education for Physicians (AAP)</b>
Session Description	This interactive session will focus on the topic of developing effective continuing medical education credits and other educational methods for physicians, and related delivery modalities. <b>Traditional methods of delivery modalities (such as conference sessions, workshops, and seminars will be presented.) A discussion of innovative ideas for developing new strategies for providing CMEs (i.e. grand rounds, workshops, web seminars, and teleconferences) will also take place between participants in this workshop. A list of current AAP CME offerings will be provided to the participants.</b>
Speaker	Suzanne Ziemnik
Session Code	PL4

Session Title	<b>“EHDI Research Updates and Opportunities”</b>
Session Description	This plenary session will <b>update participants on current research activities including the evaluation of current newborn hearing screening technology, investigation into the genetic causes of hearing loss, and EHDI program cost evaluation.</b> The session will include highlights of <b>future research opportunities including the assessment of intervention options through long term follow up of children with hearing loss</b> , and will include discussion about potential research topics.
Moderator	Krista R. Biernath
Speakers	Aileen Kenneson, Scott Grosse, Mary Pat Moeller
	<b>Workshop Breakout Sessions</b>
Session Code	
Session Title	<b>Hearing Head Start</b>
Session Description	The Hearing Head Start Project has the goal of working collaboratively with Early Head Start, Migrant Head Start, and American Indian Head Start programs serving children birth to three years old to enhance current practices in hearing screening and follow-up. Designed as a two-year endeavor, this project was funded beginning in September 2001 by the Head Start Bureau (HSB) in conjunction with Maternal and Child Health Bureau (MCHB) to test the feasibility of providing reliable screening and referral for follow-up diagnostic and intervention services within the Head Start infrastructure. A sample of centers from Utah, Oregon, and Washington are participating in the project over the two years. The results of the study will not only address the feasibility of enhanced routine early childhood screening within Head Start programs, but will also provide improved collaboration within early childhood communities within the three project states.
Speaker	Terry Foust, William Eiserman
Session Code	B2
Session Title	<b>Early Intervention</b>
Session Description	Three different models of state-based early intervention services will be presented in this session. <b>Wyoming utilizes an innovative approach providing feedback for parents by videotaping the parent's interactions with their child who has a hearing loss.</b> This allows the early intervention specialist <b>to provide support and suggestions without needing to be on-site</b> with the child and parents. <b>Colorado has developed a regional deaf role model program, which offers support and education to families on a regional basis.</b> They have also <b>trained professionals to work with infants who have hearing loss</b> , and are providing parent support to families who speak only Spanish. <b>An early intervention program for children with hearing loss is operated by the Idaho School for the Deaf and Blind.</b> There is an <b>outreach program</b> which serves families who have a child, birth to five years. The <b>philosophy of the program is that each family should have the opportunity to obtain comprehensive services regardless of the mode of communication they use.</b> The goal is for every family member to be able to communicate fully with the child who has a hearing loss.
Moderator	Karen Ditty
Speakers	Arlene Stredler Brown, Emma Lozada, Nancy R. Pajak
Session Code	B3
Session Title	<b>Web and non-Web-based EHDI Data Systems</b>

Session Description	The workshop will focus on: 1) components of EHDI tracking and surveillance systems (e.g., <b>tracking database for hearing screening and hearing loss registry; reporting by hospitals, audiologists and health care providers; reminder systems and statistical reports</b> ), 2) approaches in data collection and communication (e.g., <b>use of blood spot cards, electronic birth certificates, scanning of paper forms, and Web-based reporting and access</b> ), 3) issues that are related to data collection and tracking (e.g., <b>linkage and integration with birth certificates, privacy/confidentiality, consent requirements, data quality</b> ).
Speakers	Roy Ing, Pam Costa
Session Code	B4
Session Title	<b>Ensuring Families are Connected to a Medical Home</b>
Session Description	Two different strategies for assuring that a medical home is well informed of children with hearing loss will be presented. <b>New Jersey has developed an effective case management system for linking infants to a medical home. Utilizing the electronic birth certificate data</b> , the Department of Health and Senior Services is able to track and verify that a primary care provider is recorded for each child with a hearing loss. The case managers covering each county for Special Child Health Services, are responsible for ensuring that all infants identified through EHDI have a medical home. <b>In New Mexico, telemedicine technology is utilized to train physicians to provide a medical home for children with hearing loss. The state tracking system identifies who the medical home provider is for each child</b> , including the New Mexico Clinic sites being partially funded by a grant from MCHB.
Moderator	Bonnie Strickland
Speaker	Julia Hecht, Bonnie Teman, Leslie Beres-Sochka
Session Code	B5
Session Title	<b>EHDI Check Up: Examining the Health of Your State Law (AAP)</b>
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Speakers	James G. Pawelski, Judith C. Dolins, Dolores Orfanakis
Session Code	B6
Session Title	<b>Cochlear Implant and Meningitis Investigation Update</b>
Session Description	In <b>July 2002, the U.S. Food and Drug Administration (FDA) issued a public health notification on cochlear implants and meningitis</b> . The FDA notification stated there might be an association between cochlear implants and the occurrence of bacterial meningitis. <b>Using an EPI AID model of investigation, medical information is being collected from three different sources: the cochlear implant hospitals, the meningitis hospitals (case subjects only), and primary health care providers</b> . CDC is also doing telephone interviews with the parents of case and control subjects. Information about bacterial meningitis and <b>changes in immunization recommendations (children who have or are expected to receive a cochlear implant are now included in a “high risk” group for contracting bacterial meningitis and are now recommended for the meningococcal polysaccharide vaccine)</b> .
Moderator	Krista R. Biernath

Speakers	Jennita Reefhuis, Shadi Chamany, Karen Broder
Session Title	<b>National Campaign for Hearing Health (NCHH)</b>
Session Description	The Deafness Research Foundation (DRF), sponsor of the National Campaign for Hearing Health (NCHH), invites you to learn about ways in which you can raise awareness of issues related to early detection and intervention. DRF/NCHH has educational tools, programs and publications that promote a lifetime of hearing health beginning with early detection and intervention. A non-profit organization based in Washington, D.C., DRF is the greatest source of private funding for hearing research and an active leader in public education and advocacy. Founded in 1958, DRF's mission is to make a lifetime of hearing health possible for all people through quality research, education and advocacy.
Speaker	Susan Greco

<b>Tuesday, February 25<sup>th</sup></b>	
Session Code	M3
Session Title	<b>“Sound and Fury” Documentary and Discussion</b>
Session Description	This documentary and discussion focuses on two brothers, one deaf and one hearing, who grapple with a decision concerning their deaf children. The debate that rages through the extended family turns less <b>on technology and medical concerns than social politics and culture</b> . The deaf parents of a school-age girl fear what the implant would do to her <b>unique identity</b> , while the hearing parents of a toddler see no question at all when it comes to making a lifetime commitment to a communication mode. <b>All sides have their say, but ultimately the increasingly angry arguments reveal prejudices and fears</b> from both sides and split the once-harmonious family, much like they have split hearing and deaf communities across the country.
Moderator	Sharon McNeal
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Session Title	<b>“Sound or Silence” Documentary and Discussion</b>
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Moderator	Marilyn Sass-Lehrer
Session Title	Parent and Advocates Meeting
Session Description	This meeting will provide an opportunity for advocates and parents of children with hearing loss to exchange ideas. Parents will be asked to share what helped them the most throughout the EHDI process, as their children went from screening to diagnostics to early intervention to school, and where they



	felt more assistance was needed. Advocates will be asked to share their successes, frustrations and plans with parents and the advocates from other states.
Moderator	Jennifer Cernoch
Session Code	PL 5
Session Title	<b>“The Case for EHDI: A Critical Evaluation of the Evidence”</b>
Session Description	Justification for EHDI programs has been improved speech and language development for early-identified infants with congenital hearing loss. This <b>rationale has been challenged because of design limitations of existing studies.</b> This presentation will argue that the ability to hear is itself a <b>primary health outcome</b> , that there is evidence the newborn hearing screening improves the ability to hear for infants identified with hearing loss, that speech and language improvement should not be the <b>evaluative measure for EHDI</b> , and that evidence-based practice can be <b>flawed if the principles are not correctly applied.</b>
Speaker	Martyn Hyde
Session Code	PL 6
Session Title	<b>“EHDI Tracking and Reporting”</b>
Session Description	A panel of speakers from three states will present how their EHDI Tracking and Surveillance systems are designed and implemented. The panel will describe different approaches (e.g., <b>use of blood spot cards, electronic birth certificates, scanning paper forms/FAX and Web-based system</b> ) to: (1) collect newborn hearing screening results from hospitals, audiologists, health care providers and early intervention specialists, and (2) provide feedback to health care providers and parents. The speakers will also <b>describe their experiences with their systems, and answer questions to help make recommendations for other states.</b>
Moderator	June Holstrum
Speakers	Roy Ing, Millie Sanford, Debra Lochner Doyle, Craig A. Mason
	<b>Workshop and Roundtable Breakout Sessions</b>
Session Code	C1
Session Title	<b>Web and non-Web-based EHDI Data Systems</b>
Session Description	The workshop will focus on: (1) components of EHDI tracking and surveillance systems (e.g., <b>tracking database for hearing screening and hearing loss registry; reporting by hospitals, audiologists and health care providers; reminder systems and statistical reports</b> ), (2) approaches in data collection and communication (e.g., <b>use of blood spot cards, electronic birth certificates, scanning of paper forms, and Web-based reporting and access</b> ), (3) issues that are related to data collection and tracking (e.g., <b>linkage and integration with birth certificates, privacy/confidentiality, consent requirements, data quality</b> ).
Speakers	Roy Ing, Pam Costa
Session Code	C2
Session Title	<b>Responding to the USPSTF Statement--Roundtables</b>
Session Description	In October 2001, the U.S. Preventive Services Task Force issued a report concluding that there <b>was insufficient evidence of long-term outcomes from early identification of hearing loss through newborn screening to</b>



	<b>justify a recommendation in favor of screening.</b> This session will focus on implications of the Task Force's conclusion; <b>allow discussion about the impact the statement may have had on EHDI programs (i.e. delays or changes in legislation, potential insurance/hospital refusal to include screening as part of a standard of care package).</b>
Moderator	Scott Grosse
Session Code	C3
Session Title	<b>National Resources</b>
Session Description	This session will feature speakers from three organizations that provide resources useful to EHDI programs. <b>Boys Town provides professional education and training, performance assessment and outreach services, as well as research opportunities related to hearing loss. The National Institute on Deafness and other Communication Disorders (NIDCD) is one of the Institutes that comprise the National Institutes of Health. NIDCD conducts and supports research in the normal and disordered processes of hearing, speech and language. The National Center for Hearing Assessment and Management (NCHAM) provides technical assistance</b> for states receiving MCHB grants for EHDI and has been instrumental in helping hospitals and states across the country implement EHDI programs. NCHAM has a National EHDI Assistance Network consisting of 12 audiologists throughout the country who help states in their regions implement and refine their EHDI programs. <b>Contact and website information will also be provided by all three organizations.</b>
Moderator	Karl White
Speakers	Karl White, Mary Pat Moeller, Marin P. Allen
Session Code	C4
Session Title	<b>Privacy and Confidentiality: Developing Informed Consent Materials</b>
Session Description	This workshop will focus on how to develop informed consent materials for EHDI programs by ensuring appropriate language to allow screening and subsequent data sharing for adequate follow up and outcome determinations is included in the materials. The goal will be <b>to fully consider the broad range of medical ethics issues in the context of State Health Departments both with and without state legislation regarding consents.</b> This workshop will also focus on <b>public policy issues (i.e. assuring that the consents are HIPAA and FERPA compliant).</b>
Speaker	Beverly Dozier
Session Code	C5
Session Title	<b>The Medical Home and EHDI: Ideas for Integration (AAP)</b>
Session Description	Sponsored by AAP, this workshop will focus on the topic of the Medical Home. This workshop is specifically designed for conference participants representing the 16 states that currently have state Medical Home Mentor Teams and have developed state medical home action plans. <b>Participants will introduce themselves, provide contact information, and briefly describe the medical home work being done in their respective states. Special emphasis will be placed on the process of integrating screening into the medical home and will focus on the Utah state Medical Home Mentor Team as an example of improving medical homes.</b>
Moderator	Sunnah Kim
Speakers	Vera Frances Tait, Charles E. Norlin, Gina Poley-Money

Session Code	C6
Session Title	<b>Cultural Competency</b>
Session Description	This session will focus on experiences in culture and the community, and EHDI. The panel will consider various viewpoints as they relate to EHDI, particularly the views of the deaf community, the Latino community, and the African-American community. Presenters will offer issues to consider and suggestions for how to overcome barriers (i.e., <b>language, cultural preferences, rural transportation needs</b> ). A discussion of <b>strategies for overcoming certain barriers by developing materials in various languages, tapping partner/CBO groups to represent minority groups in EHDI activity/material planning, and providing specialized training with interpreters</b> will be described.
Moderator	Barbara Raimondo
Speakers	Thomas K. Holcomb, Cynthia Ashby, Ann Swanson
Session Title	<b>National Perinatal Association Meeting</b>
Session Description	The purpose of this “by invitation only” meeting is to discuss ideas about NPA's involvement in the development of parent support directions with a focus on health specific issues and utilization of State Perinatal Associations.
Speaker	Mark Gaylord
Session Code	PL7
Session Title	<b>“Evaluation of Public Health Programs”</b>
Session Description	This seminar will introduce participants to evaluation of prevention programs, using as a guide the <b>steps in CDC’s “Framework for Program Evaluation in Public Health.”</b> Participants will be led through the steps, be presented <b>with options for approaching each step, and be presented with decision criteria for choosing among the options.</b> Mr. Chapel will <b>illustrate use of the Framework by applying its components to selected NCBDDD funded program examples including EHDI.</b>
Speaker	Thomas J. Chapel
	<b>Workshop and Roundtable Breakout Sessions</b>
Session Code	D1
Session Title	<b>Sustaining EHDI Programs--Roundtables</b>
Session Description	The EHDI project coordinator for the state of Delaware will describe her state's current planning efforts for sustaining EHDI after federal project funding is over. The state of Delaware has no mandate for EHDI. <b>By working through the state's AAP Chapter Champion, an emphasis has been placed on voluntary screening and hospital reporting to the state for tracking purposes. To sustain success, the state will work through the Champion and consultant audiologists to provide training and promote ongoing voluntary reporting not only between the hospital and the state, but also between audiologists, medical providers, and early intervention programs.</b> Delaware's plans will be briefly explained, <b>followed by an open discussion about strategic planning ideas for sustaining the participant's respective current programs</b>
Moderator	JoAnn Baker
Session Code	D2
Session Title	<b>Privacy and Confidentiality--Roundtables</b>
Session Description	In an open forum, states will have an opportunity <b>to raise unique issues they</b>

	<b>face in regards to HIPAA, FERPA, and other privacy/confidentiality laws</b> and bounce ideas of each other for handling various components of EHDI (reporting, tracking) affected by HIPAA and FERPA. Beverly Dozier, an attorney on staff with CDC's National Center on Birth Defects and Developmental Disabilities will be the facilitator of discussion and be available to <b>address any legal issues or questions</b>
Moderator	Beverly Dozier
Session Code	D3
Session Title	<b>National Resources</b>
Session Description	This session will feature speakers from three organizations that provide resources useful to EHDI programs. <b>Boys Town provides professional education and training, performance assessment and outreach services, as well as research opportunities related to hearing loss. The National Institute on Deafness and other Communication Disorders (NIDCD) is one of the Institutes that comprise the National Institutes of Health. NIDCD conducts and supports research in the normal and disordered processes of hearing, speech and language. The National Center for Hearing Assessment and Management (NCHAM) provides technical assistance</b> for states receiving MCHB grants for EHDI and has been instrumental in helping hospitals and states across the country implement EHDI programs. NCHAM has a National EHDI Assistance Network consisting of 12 audiologists throughout the country who help states in their regions implement and refine their EHDI programs. <b>Contact and website information will also be provided by all three organizations.</b>
Moderator	Karl White
Speakers	Karl White, Mary Pat Moeller, Marin P. Allen
Session Code	D4
Session Title	<b>How to Use EHDI Data</b>
Session Description	This workshop will focus on data items identified for use in EHDI systems ( <b>a list of the data items identified by the CDC EHDI Data Items Committee for EHDI Tracking and Surveillance will be provided to each participant</b> ). <b>A discussion of how data items can be used to prepare reports and summaries will take place. Participants will hear how states use data to summarize EHDI program achievements, goals, and future objectives; provide key program information to administrators, state legislators, and policy makers; raise public awareness of a state program; and provide an immediately available template to use when preparing other reports.</b>
Moderator	Sue Visser
Speakers	John Eichwald, Craig Mason
Session Code	D5
Session Title	<b>The Medical Home and EHDI: Ideas for Integration (AAP)</b>
Session Description	Sponsored by AAP, this workshop will focus on the topic of the Medical Home. This workshop is specifically designed for conference participants representing the 16 states that currently have state Medical Home Mentor Teams and have developed state medical home action plans. <b>Participants will introduce themselves, provide contact information, and briefly describe the medical home work being done in their respective states. Special emphasis will be placed on the process of integrating screening into the medical home and will focus on the Utah state Medical Home Mentor Team as an example of improving medical homes.</b>
Moderator	Sunnah Kim

Speakers	Vera Frances Tait, Charles E. Norlin, Gina Poley-Money
Session Code	D6
Session Title	<b>Cultural Competency</b>
Session Description	This session will focus on experiences in culture and the community, and EHDI. The panel will consider various viewpoints as they relate to EHDI, particularly the views of the deaf community, the Latino community, and the African-American community. Presenters will offer issues to consider and suggestions for how to overcome barriers (i.e., <b>language, cultural preferences, rural transportation needs</b> ). A discussion of <b>strategies for overcoming certain barriers by developing materials in various languages, tapping partner/CBO groups to represent minority groups in EHDI activity/material planning, and providing specialized training with interpreters</b> will be described.
Moderator	Barbara Raimondo
Speakers	Thomas K. Holcomb, Cynthia Ashby, Ann Swanson
Session Code	D7
Session Title	<b>Identifying Pediatric Audiologists</b>
Session Description	This session will assist states in identifying appropriate referral sources within their state who have the equipment, experience, and expertise for providing pediatric audiometric assessments. Examples of approaches used by state EHDI programs to generate lists of referral sources (i.e., <b>collaborating with audiologic organizations (AAA, ASHA), participating in state meetings and conferences of audiologists, maintaining open communication with area audiologists and ensuring audiologists have active roles on state EHDI planning committees</b> ) will be discussed. The <b>positive impact</b> of having referral sources will also be addressed. <b>Decreasing the number of children lost to follow up, and more timely follow up conducted by skilled professional audiologists will ensure more accurate and timely diagnosis.</b>
Moderator	Faye McCollister
Speakers	Thomas Mahoney, Mary Jane Sullivan

<b>Wednesday, February 26<sup>th</sup></b>	
Session Code	M5
Session Title	<b>“Sound and Fury” Documentary and Discussion</b>
Session Description	This documentary and discussion focuses on two brothers, one deaf and one hearing, who grapple with a decision concerning their deaf children. The debate that rages through the extended family turns less <b>on technology and medical concerns than social politics and culture</b> . The deaf parents of a school-age girl fear what the implant would do to her <b>unique identity</b> , while the hearing parents of a toddler see no question at all when it comes to making a lifetime commitment to a communication mode. <b>All sides have their say, but ultimately the increasingly angry arguments reveal prejudices and fears</b> from both sides and split the once-harmonious family, much like they have split hearing and deaf communities across the country.
Moderator	Sharon McNeal
Session Code	V6
Session Title	<b>“Sound or Silence” Documentary and Discussion</b>
Session Description	This documentary focuses on the decision-making process of adults

	considering cochlear implants and of parents determining the communication mode that is most suitable for their child(ren). <b>The issues and emotions (fear, isolation, awareness of deaf culture)</b> involved in assessing the options available and the consequences of the choices made will be discussed by families who have been faced with this difficult process. One woman's life is followed as she gathers information about cochlear implants, <b>faces the fear of surgery involving the brain, along with the hope of being able to hear once again.</b> Ultimately she has the surgery, then realizes she will need to re-learn how to hear as well as speak. <b>Fear, anger, frustration, hope, and joy are all real emotions faced by families when making choices about lifetime communication commitments.</b>
Moderator	Marilyn Sass-Lehrer
Session Code	PL8
Session Title	<b>"The Genetics of Hearing Loss"</b>
Session Description	This presentation will look at the genetics of hearing loss. Historically, epidemiologic studies of permanent childhood hearing loss have attributed approximately 50% of the cases to a genetic etiology. <b>A discussion of the kinds of genetic hearing loss will be presented—genetic hearing loss may be delayed or congenital in onset; conductive, sensorineural or mixed in type; mild to profound in degree; stable or progressive over time; unilateral or bilateral; symmetric or asymmetric in audiogram configuration; and syndromic or non-syndromic.</b> The presentation will detail the purpose and reason for conducting a <b>genetic evaluation of infants with confirmed hearing loss of uncertain etiology.</b> The purpose of an evaluation is to help determine the etiology of hearing loss. It is important for a knowledge geneticist to inform parents of the genetic test results to ensure a careful history with construction of a family pedigree is included as part of the genetic testing and to protect the privacy of involved family members.
Speaker	Patrick Brookhouser
<b>CONCURRENT WORKSHOP/ROUNDTABLE SESSIONS</b>	
Session Code	E1
Session Title	<b>Bringing Families Together</b>
Session Description	<b>The state of Alabama uses the services of the Alabama Ear Institute to help families of newly diagnosed children with hearing loss connect with families who have been through the same experience</b> of learning that their child has a hearing loss. <b>Regional support groups</b> are available for parents as they face decisions that will affect every family member, not just the child with hearing loss. <b>A mentoring system</b> is set up, so that new parents have someone they can call to answer questions or share emotions about what they are experiencing. <b>The state of Michigan has funded a position for a parent consultant.</b> Parents whose child is diagnosed with a hearing loss receive a card inviting them to <b>call the parent consultant, who can answer questions and provide emotional support.</b> The parent consultant serves as <b>liaison between the EHDI program, parent groups and agencies serving children with hearing loss.</b> The parent consultant is the mother of a child who is hard of hearing.
Moderator	Karen Munoz
Speakers	Casey Arnold, Debra Bailey, Amy Lester

Session Code	E3
Session Title	<b>Developing and Providing Unbiased Information</b>
Session Description	This session will focus on how states can develop and provide unbiased information to parents regarding early hearing detection and intervention. <b>The role of the audiologist, physician, state, and early intervention programs is to seek input from a diverse group of professionals, families, persons with deafness when developing materials</b> to ensure that families are provided with an unbiased array of communication options. <b>Current biases include professional preferences for one communication mode over another (i.e., medical intervention versus using sign language). Factors that affect decision-making and should be considered when developing materials include deaf culture, religious and cultural background, family needs, financial barriers.</b>
Moderator	Krista Biernath
Speaker	Rosalyn Proctor; Anne McNally
Session Code	E4
Session Title	<b>Ensuring Families are Connected to a Medical Home</b>
Session Description	Two different strategies for assuring that a medical home is well informed of children with hearing loss will be presented. <b>New Jersey has developed an effective case management system for linking infants to a medical home. Utilizing the electronic birth certificate data,</b> the Department of Health and Senior Services is able to track and verify that a primary care provider is recorded for each child with a hearing loss. The case managers covering each county for Special Child Health Services, are responsible for ensuring that all infants identified through EHDI have a medical home. <b>In New Mexico, telemedicine technology is utilized to train physicians to provide a medical home for children with hearing loss. The state tracking system identifies who the medical home provider is for each child,</b> including the New Mexico Clinic sites being partially funded by a grant from MCHB.
Moderator	Bonnie Strickland
Speakers	Julia Hecht, Bonnie Teman, Leslie Beres-Sochka
Session Code	E5
Session Title	<b>How to Use EHDI Data</b>
Session Description	This workshop will focus on data items identified for use in EHDI systems ( <b>a list of the data items identified by the CDC EHDI Data Items Committee for EHDI Tracking and Surveillance will be provided to each participant</b> ). <b>A discussion of how data items can be used to prepare reports and summaries will take place. Participants will hear how states use data to summarize EHDI program achievements, goals, and future objectives; provide key program information to administrators, state legislators, and policy makers; raise public awareness of a state program; and provide an immediately available template to use when preparing other reports.</b>
Moderator	Sue Visser
Speakers	Craig A. Mason, John G. Eichwald
Session Code	E6
Session Title	<b>Involving Deaf/Hard of Hearing Communities--Roundtables</b>
Session Description	This session will include a discussion on how to get deaf and hard of hearing communities involved in state-based EHDI programs as well as discussion regarding the multiple communication modes used among the deaf/hard of hearing communities. <b>Strategies for involving deaf/hard of hearing</b>

	communities may include, but are not limited to, working with Schools of the Deaf, involving parents of children with hearing loss on planning committees, participating in health fairs for the deaf/hard of hearing communities, conducting parent to parent support groups, etc. The range of communication modes used by these special communities will also be described (i.e., ASL, total communication, oral, gestural speech, cued speech, etc.).
Moderator	Marilyn Sass-Lehrer
Session Code	E7
Session Title	<b>Sustaining EHDI Programs--Roundtables</b>
Session Description	The state of Idaho has no mandate for EHDI. They have built their program on the premise that each hospital is providing screening because it is the standard of care. The federal funding they have received has been utilized as start up money that would only be temporarily available, so emphasis has been on training and on establishing the connections to state funded agencies necessary to run an effective program. Their experience and plans will be briefly explained, followed by a <b>discussion of strategic planning for sustaining current programs.</b>
Moderator	Bee Biggs-Jarrell
Session Code	PL9
Session Title	<b>"Parent Perspectives on EHDI and Communication Choices"</b>
Session Description	Three mothers will share their experiences as parents of children who have hearing loss and describe at <b>what point in the EHDI process they needed or wanted support (at screening, diagnosis, or at or beyond early intervention)</b> , and which professionals (or other parents) they needed that support from. One mother, who moved smoothly through the EHDI system and have avoided delays in speech and language because of early identification and intervention, will describe her experience. One mother has a child who received a cochlear implant. The third mother has a daughter who has used various modes of communication, based on her developmental needs. <b>All three mothers will share their experiences going through the EHDI process from the parental perspective, including what went well and what could have been smoother. Each will discuss what professionals could do to make the early diagnosis and management of hearing loss a smoother process.</b>
Moderator	Terry Foust
Speakers	Stephanie Disney, Debra Hofmeister, Katherine Baldwin